

Supporting People with Long Term Conditions



An NHS and Social Care Model to support local innovation
and integration

**Improving Care
Improving Lives**

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Policy	Estates
HR/Workforce	Performance
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Document Purpose	Policy
ROCR Ref:	Gateway Reference: 4230
Title	Supporting People with Long Term Conditions. An NHS and Social Care Model to support local innovation and integration
Author	Department of Health
Publication Date	05 Jan 2005
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, PCT PEC Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads, Local Authorities
Description	The NHS and Social Care Model is a blueprint to support local NHS and social care organisations in improving local services for people with long term conditions. It draws on existing successes and innovations from the NHS and social care and international experience to help local health communities to develop a more integrated and systematic approach.
Cross Ref	'Improving Chronic Disease Management' – a DH policy paper issued in March 2004; 'Chronic Disease Management: A Compendium of Information' issued in May 2004.
Superseded Docs	N/A
Action Required	N/A
Timing	N/A
Contact Details	Long Term Conditions Team Primary Care, Department of Health Room 4N26 Quarry House, Quarry Hill Leeds LS2 7UE 0113 254 6070
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264799 1p 2k Jan 05 (M)

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First published: January 2005

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“When you leave the clinic, you still have a long term condition. When the visiting nurse leaves your home, you still have a long term condition. In the middle of the night, you fight the pain alone. At the weekend, you manage without your home help. Living with a long term condition is a great deal more than medical or professional assistance.”

*Harry Cayton,
Director for Patients and the Public, Department of Health*

Seventeen and a half million people in this country report living with a long term condition. Of these, many live with a condition that limits their ability to cope with day-to-day activities. For some people, especially older people and those who have more than one condition, discomfort and stress is an everyday reality. For those living in disadvantaged circumstances or for whom English is not their first language, the challenges are even greater. And for the most vulnerable, a lack of co-ordinated, personalised care can lead to a significant deterioration in health and often avoidable emergency admissions.



It is important to recognise that health and social care teams across the country are routinely offering quality care to these patients. Examples of local excellence are not hard to find, including care provided by general practice to its registered population, progress in implementing the National Service Frameworks and support from social care. But now, as with the global health community, the NHS and its partners in social care and the voluntary sector face a crucial junction as the incidence of long term conditions is set to increase. This is why the NHS Improvement Plan, published in June last year, set out the government's priority to improve care for people with long term conditions by moving away from reactive care based in acute systems, towards a systematic, patient-centred approach. Care needs to be rooted in primary care settings and underpinned by vastly improved communication and new partnerships across the whole health and social care spectrum.

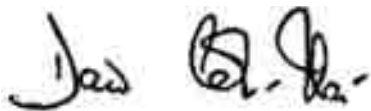
Centrally, the government has taken the lead in setting the national Public Service Agreement (PSA) target for improving outcomes for people with long term conditions by offering a personalised care plan for vulnerable people most at risk, and to reduce emergency bed days by 5% by 2008 through improved care in primary and community settings. Linked to this is the older people's PSA target to increase the number of people over 65 supported to live at home by 1% a year in 2007 and 2008. To take this forward, this document sets out a new bespoke NHS and Social Care Model designed to help local NHS and social care organisations improve care for people with long term conditions. This Model builds on the existing successes, experiences and innovations of the NHS and social care and focuses on helping health communities use the tools they already have to develop a targeted systematic approach to care for their chronically-ill populations.

But one size never fits all, and the Model provides for flexibility in how PCTs and partner organisations deliver. Matching care to need is key. For the majority of people with long term conditions, significant benefits come from getting better, more integrated support for managing their own symptoms and medication. Initiatives such as the Expert Patient Programme are leading to better health for patients, better medicines taking, fewer complications and a greater sense of control in coping with day-to-day illness.

There are now some early and vital steps we need to take to identify those most at risk who have complex and high intensity needs and who may not currently be served well by the NHS. The NHS Improvement Plan identified that 5% of patients who stay in hospital account for 42% of hospital stays. This is distressing for patients, and costly to the NHS. Health and social care communities are therefore being encouraged to adopt case management approaches now as a means of ensuring these patients get fully joined-up health and social care.

Improved support for people with long term conditions will demand wholesale change in the way health and social care services deliver care. However, there are big rewards to be reaped for patients, health and social care services and professionals alike. In doing so, the NHS and social care will become one of the biggest health communities to implement a systematic long term condition model. We are still learning from others about individual elements of the model. As we progress, we must continue to gather our own best practice to identify and share learning. This will take us into the forefront of international progress and innovation.

The challenge is to work across boundaries – both cultural and organisational – and develop the integrated, patient-centred services which will transform care for this growing group of people.

A handwritten signature in black ink, appearing to read 'David Colin-Thomé'.

David Colin-Thomé, GP
National Clinical Director for Primary Care
January 2005

The problem

- Seventeen and a half million people in this country report a long term condition (such as diabetes, asthma or arthritis).
- For some people, especially older people and those with more than one condition, discomfort and stress is an everyday reality.
- The impact on the NHS and social care for supporting people with long term conditions is significant.
- Care for many people with long term conditions has traditionally been reactive, unplanned and episodic. This has resulted in heavy use of secondary care services.
- Just 5% of inpatients, many with a long term condition, account for 42% of all acute bed days.
- Only about 50% of medicines are taken as prescribed.

The specific target

- The PSA target is to reduce inpatient emergency bed days by 5% by March 2008 using 2003/04 as the baseline.
- Health communities are expected to make progress towards the PSA target from 2005 onwards by offering a personalised care plan for vulnerable people most at risk.

The strategic aim

- To embed into local health and social care communities an effective, systematic approach to the care and management of patients with a long term condition.
- To reduce the reliance on secondary care services and increase the provision of care in a primary, community or home environment.
- Patients with long term conditions need high-quality care personalised to meet their individual requirements.
- The Public Health White Paper 'Choosing Health' underpins the entire long term condition approach. This will build on the public's growing desire for a healthier future by ensuring that the self care support is in place for people – particularly those in disadvantaged groups and areas – to make healthier choices about diet, physical activity and lifestyle.

Key aspects of the NHS and Social Care Long Term Conditions Model

- Identify all long term condition patients in your health community.
- Stratify the patients to match care to different needs of patients
- **Level 3: Case management** – Identify the most vulnerable people, those with highly complex multiple long term conditions, and use a case management approach, to anticipate, co-ordinate and join up health and social care.
- **Level 2: Disease-specific care management** – This involves providing people who have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways, such as the National Service Frameworks and Quality and Outcomes Framework.
- **Level 1: Supported self care** – collaboratively help individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively.
- Focus initially on the very high intensive users of secondary care services through a case management approach.
- Appoint community matrons to spearhead the case management drive. In total, there will be 3000 community matrons in post by March 2007.
- Over time, develop a system of identifying prospective very high intensity users of services.
- Establish multi-professional teams based in primary or community care with support of specialist advice to manage care across all settings.
- Develop a local strategy to support comprehensive self care.
- Implement the Expert Patient Programme and other self care programmes.
- Take a systematic approach that links health, social care, patients and carers.
- Use the tools and techniques already available to start to make an impact.

An NHS and Social Care Model for improving care for people with long term conditions

Key Actions

1. The NHS and Social Care Long Term Conditions Model will help ensure health and social care organisations take an overall structured and systematic approach to improving the care of those with long term conditions.
2. Health and social care organisations should take action now to ensure that the model is implemented.
3. To deliver the PSA target and have a significant impact on the way the health system works action needs to start now.
4. The immediate focus should be the introduction of case management for the most vulnerable people with complex long term conditions.
5. Significant numbers of hospital admissions relate to long term conditions and can be avoided.

Strong general practice, social services, community nursing and hospital out reach services are at the heart of high quality services for patients with long term conditions. The National Service Frameworks (NSF) are already demonstrating that new systems and approaches in primary care can have a radical improvement on outcomes for patients. The NHS and social care are paving the way towards better care and improved lives for patients with long term conditions. However, more needs to be done to establish a robust, systematic approach.

What are we trying to achieve?

We should aim to treat patients sooner, nearer to home and earlier in the course of disease. To do this we need a combination of:

- earlier detection;
- good control to minimise effects of disease and reduce complications;
- more effective medicines management;
- reduction in the number of crises;
- promoting independence, empowering patients and allowing them to take control of their lives, and
- prolonging and extending the quality of life.

In summary, we want to give patients the most intensive care in the least intensive setting.

To do this we need to move away from a *reactive, unplanned* and *episodic* approach to care, particularly for those with complex conditions and high intensity needs. For example, eight of the top eleven causes of hospital admissions are long term conditions. The services are there to help them when their condition reaches crisis point, but often fail to provide the on-going, co-ordinated support needed to prevent such crises from happening in the first place.

The NHS and Social Care Long Term Conditions Model

The NHS and Social Care Long Term Conditions Model builds on the wealth of local and international experiences and innovations,¹ to improve the health and quality of life of those with long term conditions. For example, it reflects learning from US models such as Evercare and Kaiser Permanente. However, the values and structures of the NHS are different. The Model therefore also reflects the strengths of the existing infrastructures and services, particularly in primary and community care, unique to this country. The purpose of the Model is to improve the health and quality of life of those with long term conditions by providing personalised, yet systematic on-going support, based on what works best for people in NHS and social care systems.

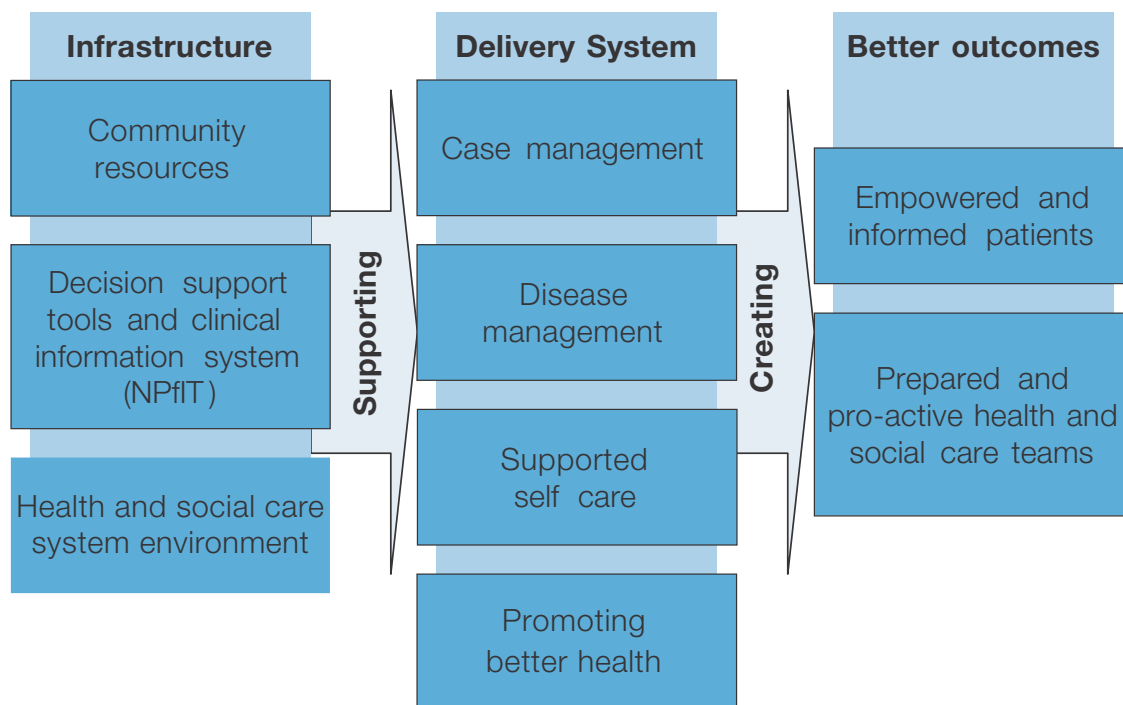
The Model will help ensure effective joint working between all those involved in delivering care – including secondary care, ambulance trusts, social care and voluntary and community organisations – so patients experience a seamless journey through the health and social care systems.

The first priority should be to introduce a system of case management that will help those with most complex needs, help deliver the PSA target, and have the greatest impact on the way the health system works.

The Model provides a structured and consistent approach to help local health and social care partners shape the way they deliver integrated long term care locally. It details the infrastructure available to support better care for those with long term conditions as well as a delivery system designed to match support with patient need.

¹ The NHS and Social Care Long Term Conditions Model reflects the wealth of experience that already exists in the NHS and among its social care partners. It draws on the 'chronic care model' researched and applied by Professor Wagner and colleagues in Seattle, USA, which shows how patients, health care providers and community organisations can interact to deliver better systems of care. It also draws on the 'pyramid of care' developed by US health provider Kaiser Permanente which identifies the population of patients with long term conditions into three distinct groups based on their degree of need.

The NHS and Social Care Long Term Conditions Model



The levers for achieving this are empowered and informed individuals working in partnership with prepared and pro-active health and social care teams.

NHS and social care organisations are already showing how they can adapt this model to their needs. To gain the most benefit organisations will need to systematically link activity rather than work on individual initiatives. This document focuses on delivery system design.

The delivery system is the aspect of supporting people with long term conditions that most experts agree is a good place to start. Further elements of the infrastructure of the NHS and Social Care Long Term Conditions Model will be issued as supplements to this document. This will include the publication later this year of the NSF for Long Term Conditions and its supporting good practice guidance. The NSF will focus on improving services for people with long term neurological conditions but much of the guidance it offers can apply to anyone living with a long term condition.

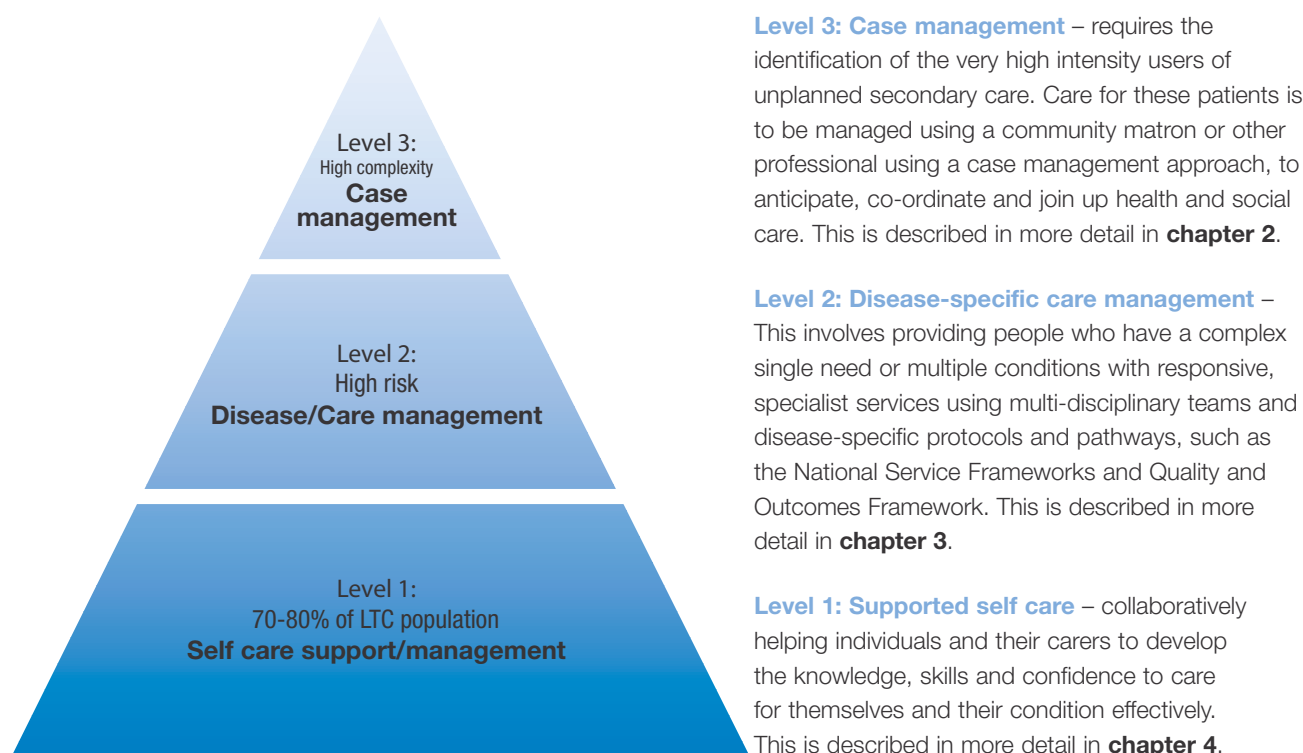
The National Primary Care Development Team (NPDT) also highlights this systematic approach as an important lever to the delivery of improved management of long term conditions at both PCT and practice level. In particular, the work of the National Primary Care Collaborative (NPCC) has ensured that a significant number of PCTs and practices are working in a systematic way to deliver improved care for patients. The Model builds on this important principle.

Delivery system

The recommended route to deliver a systematic approach is to utilise multi-professional teams and integrated patient pathways to ensure closer integration between health and social care. All health and social care services should begin to adopt this approach.

Different interventions should then be used for patients with different degrees of need. The NHS and Social Care Long Term Conditions Model sets out a delivery system that matches care with need.

NHS and social care organisations will be familiar with the Kaiser Permanente triangle. The Model builds on this approach.



Underpinned by promoting better health – building on the public's growing desire for a healthier future by ensuring that the self care support is in place for people – particularly those in disadvantaged groups and areas – to make healthier choices about diet, physical activity and lifestyle, for example stopping smoking and reducing alcohol intake. *Choosing Health* provides invaluable guidance in this area and the new pharmacy contractual framework includes the promotion of healthy life-styles as an *essential service* which all pharmacies will provide.

Infrastructure

Community resources:

Voluntary, community and patient organisations will enhance the support available locally to people and their carers. Community resources such as patient groups will also help considerably by being involved in service delivery redesign.

Decision support and clinical information systems (NPfIT):

Organisations will build on the use of evidence-based national guidelines, such as the National Service Frameworks, NICE guidance and Quality and Outcomes Framework, to be supported by local guidelines to provide standards for optimal care. Organisations need to use data, preferably held electronically, to facilitate more efficient and effective management of care through patient registers, recall and reminder systems and feedback to clinicians.

Health and social care system environment:

Organisations need to use the tools available to better organise health services. This will include 'payment by results' to move resources and the new GMS and pharmacy contracts. In addition, we would expect to see the development of pooled budgets across health and social care to build flexibility. Practice-based commissioning will bring front line clinicians into the commissioning and redesign process and the choice policy will enable patients to take greater control of their condition. Community matrons and other case managers will need to have the authority to secure services for patients at the time needed and to order investigations, make referrals and arrange admissions on behalf of patients.

Case management for patients with complex long term conditions and high intensity needs

Key Actions

1. Identify patients with complex conditions who are most at high risk of unplanned admissions or long term institutionalisation.
2. Develop the role of community matron in your locality.
3. Use this information to draw up a plan of how this new service will be introduced and integrated with existing services. This should project the impact case management will have on hospital admissions and lengths of stay.

As patients develop multiple long term conditions, their care becomes disproportionately complex and can be difficult for them and the health and social care system to manage. Such patients have an intricate mix of health and social care difficulties. Because of their vulnerability, simple problems can make their condition deteriorate rapidly, putting them at high risk of unplanned hospital admissions or long term institutionalisation. This is often older people, but could also include children and patients with complex neurological conditions or mental health problems.

Evidence has shown that intensive, on-going and personalised case management can improve the quality of life and outcomes for these patients, dramatically reducing emergency admissions and enabling patients who are admitted to return home more quickly.

For this reason, the introduction of community matrons applying a case management approach will play a significant role in helping local health communities achieve the PSA target for improving care for patients with long term conditions, and in reducing the use of emergency bed days by 5% by 2008. Case management is also the first step to creating an effective delivery system and implementing the wider NHS and Social Care Long Term Conditions Model.

Steps to implementing case management

As the model of care shows, this high risk group of patients needs not only good management of their specific diseases, but also a holistic overview to be taken of their full health and social care needs. Their care should go beyond the clinical to encompass the full range of factors that affect them such as their ability to maintain personal interests and social contact.

Key to meeting the needs of these patients is a case manager. Patients in this group often have a combination of medical, nursing, pharmacy and social care needs and nurses, as community matrons, are ideally placed to meet the range of needs without fragmenting care. It is recognised that other professionals may also take on a case management role for this group of patients. However, where the clinical needs of these patients are high, we expect that community matrons will take on the case management role.

Step 1: Identifying the most vulnerable patients

Health and social care organisations need to develop ways of identifying patients with the most complex conditions who are most at risk of admission to hospital or institutionalisation. These are the patients who will most benefit from case management.

Health and social care partners will **first** need to agree the most appropriate criteria for selecting these people, drawing on the good practice already established in different parts of the country. This can happen now. The criteria are likely to take account of:

- how often a patient is admitted to hospital and the length of their stay;
- the number of medical and other problems a patient has (co-morbidity);
- the number of medicines a patient takes (or fails to take and the reasons for not taking them);
- the number of times a patient consults their GP about their condition, and
- other high risk factors such as the death of a patient's carer.

Data sources should include GP records and district nursing records, as well as hospital discharge records.

Health and social care organisations need to ensure they do not overlook any 'hidden populations' of vulnerable patients. Many of the areas which have been piloting case management using nurses have identified high-risk patients who tended to be known to one part of the service but were not known, or being actively managed by, the whole care system. For example, only 24% of patients treated under the NHS-adapted Evercare pilots² were on active district nursing caseloads, and only 35% were known to social services. The pilots have highlighted that data about high-risk patients does exist

² Evercare is one model of case management. Health and social care organisations should adopt the principles of case management (adapted to local NHS and social care circumstances) set out in this document rather than any particular model.

in PCT systems, but not in a ready form. This suggests a need for more systematic tools and processes for extracting data and enhanced data management skills within PCTs.

Increasingly we will see software developments internally and externally to the NHS to support this task. Analysis shows that identifying high risk patients may not be static; many will recover. Similarly, other high risk patients will emerge. The Department will work with Strategic Health Authorities to identify whether to specify one approach to be used consistently across the country to allow progress to be compared. We will provide an update to this document if this is the case. In the meantime, health and social care partners should use the above criteria to identify most at risk patients.

Case study

Castlefields Health Centre in Runcorn

Here a nurse, working closely with a social worker, considers patients eligible for case management if they are over 65 and meet at least three of the following criteria:

- four or more active long term conditions;
- four or more medicines, prescribed for six months or more;
- two or more hospital admissions, not necessarily as an emergency, in the past 12 months;
- two or more A&E attendances in the past 12 months;
- significant impairment in one or more major activity involved in daily living;
- significant impairment in one or more of the instrumental activities of living, particularly where no support systems are in place;
- older people in the top 3% of frequent visitors to the practice;
- older people who have had two or more outpatient appointments;
- older people whose total stay in hospital exceeded four weeks in a year;
- older people whose social work contact exceeded four assessment visits in each three month period, and
- older people whose prescribing costs exceeded £100 per month.

Case Study

NHS Evercare Pilots

Here, each PCT identified people 65+ who had two or more unplanned hospital admissions in the last 13 months (from 1 Jan 2002 to 31 Jan 2003).

Additional criteria were developed to nominate patients into the high-risk caseload of the nurses who were the case managers. GPs were given nomination criteria as guidelines for the inclusion of more patients in the high-risk caseload. Any one of the following four criteria were reasons to nominate a person into the high-risk caseload:

- recent exacerbation or decompensation of chronic illness (within last 90 days);
- recent falls: >2 falls in 2 months;
- recently bereaved and at risk of medical decline (death of a spouse or family member in past 6 months), and
- cognitively impaired, living alone, medically unstable, and high intensity social service package.



Lisa Brookes, Community Nurse.

Step 2: Develop the community matron role

Community matrons are likely to have caseloads of around 50-80 patients with the most complex needs and who require clinical intervention as well as care co-ordination. They will work across health and social care services and the voluntary sector, so that this group of patients receives services that are integrated and complementary. Whether they work from the PCT, general practice or a hospital, community matrons need to have close working relationships with general practice, hospital wards and local social services teams.

The role of a community matron

They:

Work collaboratively with all professionals, carers and relatives to understand all aspects of the patient's physical, emotional and social situation.

Develop a personalised care plan with the patient, carers, relatives and health and social care professionals, based on a full assessment of medical, nursing and care needs. The plan includes preventative measures and anticipates any future needs the patient may have.

Keep in touch with the patient and monitor their condition regularly. This may be done by home visits or by telephone contact.

Initiate action if required, such as ordering tests or prescribing.

Update the patient's medical records, including medicines review, and inform other professionals about changes in condition.

Liaise with other local agencies such as social services and the voluntary and community sectors, to mobilise resources as they are needed.

Teach carers and relatives to recognise subtle changes in the patient's condition that could lead to an acute deterioration in their health, and to call for help.

Secure additional support as needed, for example, from home care, intermediate care or palliative care teams, or geriatricians.

Maintain contact with the patient if s/he is admitted to hospital and give the unit treating the patient the information they need to ensure integrated and consistent care.

Community matrons can come from any branch of nursing. However district nurses are likely to be the single largest group who will most easily make the transition. Where this happens, arrangements will need to be in place to enhance the skills of other members of the district nursing team, including unqualified staff, so they can increase their own capacity. Community matrons may also be drawn from hospitals where experienced senior nurses have skills that can be developed for a community case manager role. Community matrons are expected to be both independent and supplementary prescribers. Steps will need to be taken to boost the numbers of qualified nurses entering primary care. Examples of how to do this are shown in the Flexible Entry to Primary Care Nursing Project Report (DH 2004).

Developing the competencies to become a community matron needs to be in keeping with the knowledge and skills framework and the skills escalator. The community matron role profile will be made available in this form.

Community matrons will need to be competent in:

- care co-ordination and case management (brokerage and provision);
- physical examination and history taking, diagnosis and treatment planning;
- managing cognitive impairment;
- using population and individual information to support decision making;
- independent and supplementary prescribing and medicines management;
- interagency and partnership working;
- management of long-term conditions (particularly the interplay between multiple diseases);
- working in the home and community settings;
- supporting self managed care;
- managing care at the end of life;
- prevention and health promotion, and
- advanced level professional practice, including self directed learning, managing risk, autonomous practice, higher level communications skills.

A self assessment tool will be made available to support nurses from both primary and secondary care services prepare to undertake the community matron role. PCTs will be able to commission local education and training based on the competencies provided by the knowledge and skills framework and the information provided by nurses completing the self assessment exercise.

A further publication providing guidance on the nursing contribution to long term conditions and the community matron role will also be available shortly.

Step 3: Carrying out thorough assessments – care planning

Once those patients most at risk have been identified, the community matron should work with them and their carers to carry out a comprehensive assessment, ie physical, social and psychological, of their current and future health and social care needs and wishes. The community matron will then draw up a care plan to reflect the personal needs and aspirations of the patient (and their carer(s)). This plan will be agreed between the patient and the community matron on behalf of the local health, social care and other agencies involved.

For many older people this approach will build on the single assessment process.

The care plan should set out the patient's agreed health objectives and care needs, including what the individual can contribute towards their own self care, and what each professional and agency will do to help them meet these. It will include preventive and health promotion actions (such as avoiding accidents, reducing infection or nutrition).

It will be owned by the individual and be reviewed regularly by the community matron in partnership with the individual (and their carer(s)). These reviews will evaluate outcomes and identify changes in the needs and wishes of the individual (and their carers).

Step 4: Co-ordinating care and services

The community matron should act as a fixed point for the patient, taking clinical responsibility for their care and co-ordinating the contribution of the different professionals who can help, anticipate and deal with their problems before they lead to worsening health or well-being.

Systematic tools and processes should be in place to help community matrons in their work. These should include:

- systems enabling them to access care for their patients quickly, such as ordering tests and investigations and mobilising social care services;
- clinical risk assessment involving patients and carers;
- processes for informing them if a high-risk patient has been admitted to hospital so they can begin planning for their discharge; and
- processes, involving primary, secondary and social care, for reviewing avoidable admissions.

The community matron should work with hospital discharge teams to ensure the patient's discharge from hospital is smooth. The patient and their carer should be actively involved in this at all stages. Appropriate care needs to be in place to ensure the patient goes to the right setting to ensure their continued recuperation and rehabilitation. The community matron should make effective use of transitional and intermediate care services so that existing acute hospital capacity is used appropriately.

Supportive and palliative care: the community matron should secure additional support where needed. This might include access to a comprehensive range of rehabilitation advice and support. For people in advanced stages, this might also include access to a comprehensive range of palliative care services which provide appropriate symptom control, pain relief and meet the needs for personal, social, psychological and spiritual support.

Action by Health communities

Health communities should draw up a detailed local plan of how this new case management service will be introduced, how it will integrate with existing services, and how rapid progress can be made in both reducing admissions and lengths of stay. Key steps to assist health communities to take this forward are set out at Annex 1.

Case Study

Case management in North West London

In just one year, an 83-year-old woman in London suffered 57 falls and came into contact with 14 different health and social care professionals.

It was only after referral to a case management pilot service at Kensington & Chelsea PCT – part of the London Older People's Service Development Programme (LOPSDP) – that some of the underlying and strikingly simple causes came to light. A lop-sided mattress causing her to roll out of bed explained why most of her falls happened in her bedroom, and a dead battery in her doorbell accounted for the numerous times she missed her weekly pharmacy delivery.

North West London SHA has been keen to see multi-disciplinary case management (CM) continue.

Their research programme showed:

- case management could release significant capacity in local inpatient services – leading to reductions of between 7.5% and 16.6% in occupied bed days in medical specialties;
- for each PCT this capacity would be worth up to £1.15 million per year, and
- indicative costs of setting up a CM service was around £173,000.

“Many of the existing models of case management are health focused,” says Steve Arnold. “But for many, chronic disease is not about a single condition, it’s about lots of difficulties combined to create a vulnerable state.”

Among several projects now underway, two of the SHA's eight PCTs are linking case management techniques into their district nursing services. An inter-disciplinary Care Co-ordination Team has also been set up in Brent.

Funded by Brent Teaching PCT, the five-strong team manages a caseload of vulnerable older people across acute and community health, social and voluntary care, building integrated and user-focused care plans.



*Yvette Beckley,
Care Co-ordinator, Brent*

The National Primary Care Contracting Collaborative – UNIQUE CARE Programme

The National Primary Care Contracting Collaborative (NPCCC) has recently commenced with a key focus on improving the care of patients with a long term condition. A major element of this programme has been the development of 'Unique Care'. This approach to practice-based management of individual patients takes an intensive, co-ordinated approach to their unique health and social care needs. The key factor is bringing together health care and social services to respond jointly to the needs of patients.

All referrals are directed to a care team comprising of a social worker and a district nurse serving a practice's or a cluster of practices' population of over sixty-fives. This case management approach means any long term condition patient admitted to hospital for an unplanned admission is followed up in the hospital by the primary care team to ensure continuity of care and to facilitate early, safe discharge. The approach fits within the development of the community matron role and the emphasis on case management of patients with the greatest needs.

In keeping with the emphasis in the NHS and Social Care Long Term Conditions Model the NPDT are working with practices to identify patients of potentially high need before they are referred for assessment or experience an acute admission. Using locally agreed criteria including number of chronic diseases, previous admission, social circumstances, number of medications etc., patients are identified for assessment by the care team.

Disease specific care management: improving pathways and protocols

Key Actions

1. Examine how disease management is currently delivered and how it can be improved.
2. Establish multi-professional teams based in primary or community care with support of specialist advice to manage care across all settings.
3. Identify patients needing disease management and provide pro-active care using agreed clinical standards and protocols.
4. Recall patients to ensure they get the care they need by using prompts and reminders.
5. Review patients regularly to ensure they receive the best evidence based care and are supported to manage their condition.
6. Look to National Service Frameworks, new primary care and pharmacy contracts for more detailed steps and approaches.

Pro-active disease management can make a real difference to patients with a single condition or a range of problems that threaten their health and well-being. Implementation of the National Service Frameworks is already demonstrating that this approach can have a radical impact on outcomes for patients. Extending disease management approaches is essential to sustaining delivery of the PSA target in order to produce better health outcomes, slow disease progression, reduce disability, ensure better management of the sudden deteriorations often associated with long term conditions and result in improved quality of life for patients and reduced need for admission to hospital.

Good care management for this group involves identifying their needs early and responding promptly with the right care and support with systematic and tailored programmes for individual patients.

In most cases, support for these patients will be from multi-disciplinary teams based in primary or community care, with the support of specialist advice, including from liaison workers such as a diabetes nurse. Experience has shown the benefit of designating a member of the care team as a named contact for the patient.

These teams will give patients pro-active care, following established pathways and protocols, to help them avoid complications or slow down the progression of their condition.

The challenge now for many PCTs and their wider health economies is to maintain and extend strategies for improving disease management locally. This will involve examining how they currently deliver disease management and identifying ways of making improvements, including by providing more diagnostic services in the community.

Case Study

Musculoskeletal services at University Hospital of North Staffordshire NHS Trust

In North Staffordshire the development of clinical teams has been an essential component in developing a cohesive service, and ensuring the most appropriate access to treatment for the patient. Clinical teams include practitioners from a wide range of specialities, for example, the musculoskeletal team includes physicians, consultant therapists and GPs with a special interest in Rheumatology. Patients have a wide range of expertise and resources available to them when working with health professional to choose the most appropriate treatment to their needs.

For example an Acute Back Pain Service initiative was developed, run by a physiotherapist working closely with medical and surgical back-up, resulting in rapid access for patients and a reduction in the spinal surgical outpatient waiting list.

Step 1: Identifying patients

Supporting this group of patients to manage their own conditions is at the heart of empowering patients, improving their experiences of services and improving their health outcomes. Delivering this support relies upon the establishment of effective practice-based registers.

Registers will provide the cornerstone of care and the basis for call and recall, clinical care, prevention, continuous quality improvement, monitoring and clinical audit.

Step 2: Following agreed clinical standards and protocols

The value of protocols in improving care for patients with long term conditions has long been recognised. The National Service Frameworks provide clear models and frameworks for a number of long term conditions and are delivering tangible improvements. The National Institute for Clinical Excellence guidance also provides many of the key clinical underpinnings for many long term conditions.

Working within these models and frameworks, PCTs and practices should develop and extend their own local disease-based protocols as part of their wider long term condition strategies.

Multi-disciplinary teams play a key role in the management of care for patients across all settings. More should be done to build on the strengths of multi-disciplinary team working with care provided in individual primary care practices supported by specialist services acting as expert resources, with pro-active support and co-ordination of services. Clinically-led, managed disease networks could provide a means of embedding such approaches locally.

People with long term conditions may be seen by many different health and social care professionals. Experience has also shown the benefit of designating one member of the care team as a named contact for each person with a long term condition. This person should act as an initial point of contact, helping the person navigate services and access other members of the multi-disciplinary team as appropriate.

Case Study

Single point of contact

A new helpdesk being set up in an ambulance dispatch centre is aiming to give GPs faster feedback about patients with long term conditions who call 999 but are not admitted to hospital.

The 'single point of contact' being piloted by Bedfordshire and Hertfordshire Ambulance and Paramedic Service will, among other roles, ensure GPs are promptly informed when frequent users of ambulance services are visited by ambulance crews.



Dean Ayres,
Project Manager, SPOC Desk

"People with long term conditions, such as epilepsy or diabetes and even mental illness can often go from being very ill to feeling much better in a short space of time," said Dean Ayres, project manager for the pilot.

The single point of contact – or SPOC desk – will be manned by a team of emergency care practitioners with direct lines of communication with GPs.

"Alerting a patient's own GP when they have contacted the ambulance service with a non-serious episode means the GP can monitor the patient more closely, reassess their care plan and help avoid an emergency admission in the future."

As well as looping patients back into their GP, the SPOC team will also have ready access to information about a range of local health and community services. This means they can advise ambulance crews quickly and over the phone about appropriate services for those patients who do not go to hospital.

Step 3: Carrying out regular clinical review, monitoring and audit

Systematic treatment regimes tailored to individual patients and their condition(s) are at the heart of better disease management. The three 'Rs' – register, recall and review – are central to this. More could be done to improve recall and review.

Recall of people is important to ensure they get the care that they need by using prompts and reminders.

Among the approaches being developed are nurse-led call centres within primary care. One component of the NatPaCT transformational change programme is the partnership between Haringey TPCT and Pfizer Ltd that has established a telephone based care management programme to support 600 patients with heart failure, coronary heart disease and diabetes. The aim of the 15 month programme, jointly funded by NatPaCT and Pfizer, is to evaluate a decision support enabled, telephone based, care management programme and the clinical, behavioural, and utilisation outcomes that can be achieved through motivating and encouraging people with long term conditions to take a more informed and active role in their healthcare. The decision support software, InformaCare, developed over a period of eight years by Pfizer Health Solutions, has been extensively adapted to fully incorporate national and local guidelines and scrutinised and approved by a Medical Advisory Panel comprising local clinicians. The team of dedicated care managers or 'health coaches' are employed by Haringey TPCT and provide regular assessment, information, motivation, and coaching interventions for patients based on their individual needs. Haringey PCT is working with Pfizer Health Solutions to develop systems to identify patients with CHD, congestive heart failure and diabetes, stay in regular contact with them and encourage better self care and medicines compliance.

Regular **review** provides an opportunity for people with long term conditions and their lead health professional to bring together all the relevant information, make sense of what it means for the individual, reviewing the content of the care plan as a result.

Increasingly PCTs are developing nurse-led, protocol-based services to support regular review services for patients with long term conditions. Managing the workload generated by reviews and maximising the numbers of patients attending has meant developing new ways to target and motivate key patient groups. South Stoke PCT has worked with the local acute trust to develop a weekly nurse-led heart failure clinic within the PCT, and, working with 20 practices in the PCT, has produced a protocol for secondary prevention of CHD.

Case Study

Specialist nurse delivering care to MS sufferers

Kathryn Crawford was diagnosed with multiple sclerosis (MS) in March 1997 and the expertise and specialist support of her MS nurse Linda Kidd have been indispensable since the start.



“A few years ago I had a significant relapse which meant I couldn’t use my left arm,” said Kathryn.

Kathryn Crawford

“It was hugely painful and I didn’t know which way to turn. Linda was able to get me oral steroids and keep an eye on me while the medication stabilised my condition – all without having to see the neurologist.”

The role of MS nurses is being supported by the Multiple Sclerosis Society’s MS Nurse Fund which has part-funded over 70 nurses and other MS specialists.

Linda has been involved in MS care for almost 20 years and says the value of an MS nurse is being able to spend more time with patients and care for them in their home.

“Another important role is joining up services for MS sufferers,” she said. “Someone who is really disabled with MS might be seeing professionals from five or six different services and be totally confused about who is doing what. We can be a gateway for them, advising about the most appropriate services and the best way to access them.”

Now Kathryn is on beta interferon and has worked with Linda to modify her injection technique and keep a close eye on side effects such as skin infections and abscesses.

She continues to work from her home office and is confident of self-managing her condition.

Supporting self care

Key Actions

1. Develop a strategy to support self care.
2. Educate and support people to manage themselves and their condition.
3. Implement Expert Patient Programme through PCTs by 2008.
4. Use Local Strategic Partnerships to strengthen multi-agency (community and voluntary organisations) support and co-ordination.
5. Look to the guidance in the Public Health White Paper.

Local health and social care partners should ensure self care and self management are priorities in local planning and commissioning and should mainstream activities to support self care. The new primary care contracting arrangements – including new GMS, PMS, PCTMS and the new pharmacy contract – will give PCTs real options for sourcing the best services to support self care.

Self care is one of the key pillars of *The NHS Improvement Plan* vision for a patient-centred care system and is an important strand to the Government's overall strategy for health. Supporting self care is essential to sustaining delivery of the PSA target in order to produce better health outcomes, slow disease progression, ensure better management of the sudden deteriorations often associated with long term conditions and result in improved quality of life for people.

For people with long term conditions, self care and self management have become increasingly important in improving well-being, maintaining independence and quality of life.

For example, patients with diabetes are relatively high users of health services. Yet each sufferer spends on average just three hours a year interacting with health professionals. For the remaining time, they and their families handle the daily challenges of the disease themselves.

**Ratio of Shared Professional Care to Self Care
across the Long Term Conditions population base.**



Understanding how to support self care

Supporting self care and self management is about more than giving patients information about their condition. It is about acknowledging their central role in managing their own care and empowering them and their family and carers to handle their condition as effectively as possible.

In order to support self care, health and social care organisations should:

- ensure patients and carers have the skills and knowledge they need to understand how to best handle their condition, including how to deal with flare-ups, to adjust medicines, improve their life-styles and access health care services;
- provide information that people are able to find easily and use meaningfully;
- enable and empower patients and their carers to manage their own condition more effectively, for example by implementing self monitoring or providing supporting prompts and reminders for patients to identify when they should be doing something and attending for care;
- provide a trusted and consistent person to contact, and
- ensure support is available from a knowledgeable patient as well as broader peer networks and community support.

Skills and knowledge

Health and social care providers will need to develop appropriate and accessible information, skills training and tools and equipment in order to empower patients and their carers to maximise their role as providers of care.

Developing generic self care skills

The Expert Patient Programme (EPP) has been central in spreading good self care and self management skills to a wider range of people with long term conditions. The programme provides group-based, generic training and is delivered by a network of trainers and volunteer tutors all living with long term conditions themselves. The EPP will be made available through all PCTs by 2008.

Educating about specific conditions

Educating patients to care for their specific condition is another important part of supporting self care. Disease-specific programmes such as Dose Adjustment for Normal Eating (DAFNE) and Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) for diabetes apply the principles of peer support, but focus on enhancing the patient's skills and confidence in managing their symptoms and medication.

Case study

Portsmouth City PCT diabetes education (group education in a practice setting)

A nurse-led service in Portsmouth is supporting practice staff to deliver group education programmes for newly-diagnosed type 2 diabetes patients and those about to start insulin treatment.

Consultant Nurse in Diabetes Sue Cradock – part of Portsmouth NHS Trust Diabetes Centre and Portsmouth City PCT – has been one of the driving forces behind a series of structured self-education programmes for patients with diabetes.

Building on their success, she is now working with a specialist diabetes nurse and a small development team in the PCT to deliver structured group education for those newly-diagnosed with type 2 diabetes and those about to start insulin treatment. The key difference is that the team are now training and supporting practice nurses and a GP to deliver group education sessions in surgery settings.



*Sunnyside Surgery, Portsmouth
City PCT diabetes education
programme*

“There is good evidence that following up patients with structured group-based education slows or reverses deterioration in the patient’s condition,” says Sue. “What we are trying to do is reap some of those benefits by using existing primary care resources to better effect.”

According to Sue, it is more difficult for patients to learn in one-to-one consultations because there is a limit to what they can take in a 20-minute slot. At the group sessions, the nurse or GP can spend a couple of hours with six or more patients without using any more resources or professional time.

Take-up for the group sessions is high with between six and 12 patients attending the practice-based programmes which are run three or four times a month. As a result of the sessions, hospital doctors are reporting that the patients are more confident about adjusting their insulin and keeping their blood sugars under control. GPs and nurses say it is easier to work with newly-diagnosed patients who have participated in the programme.

Information

By increasing the amount of information available to patients, health and social care providers can empower them to take better care of themselves and their own conditions. The EPP pilots and other local initiatives to support self care and self management have highlighted the need to pro-actively engage patients. This is not only about getting the right patients involved. It is also about ensuring that once they are ‘through the door’ they receive relevant and accessible information that meets their diverse needs.

Helping patients get the most from their medicines

Giving patients advice and support about their medicines is another important element of self management. Around half of patients with a long term condition do not take their medicines as prescribed. However, for patients to take real control of their conditions, they need fast and convenient access to medicines, involvement in decisions about those medicines, advice about how to take them and information on any side effects which they may suffer. Pharmacists have an increasing role as a source of advice for patients and their carers.

The Medicines Management Collaborative – run by the National Prescribing Centre – is focusing specifically on improving the advice and support patients get in primary care about getting the best from their medicines. The collaborative is being rolled out in waves and is already carrying out pilots in which pharmacists work with GPs to review patients’ regular medicines and to offer one-to-one reviews with patients. Early results show significant improvement in the number of patients having medication reviews (for example, from 43% to 76% in October 2004 for wave 4).

Offering diagnostics and monitoring closer to home

Increasingly health communities should make available devices necessary to help people with diagnosis, treatment and monitoring of their long term condition at home or closer to home.

Case Study

The Greater Manchester Pharmacy Project

A pilot project run by Greater Manchester SHA is making pharmacists a port of call for people managing their long term conditions.

Advances in point-of-care testing technology mean that pharmacists can now provide accurate results for tests such as glucose, cholesterol and anti-coagulant status with relatively simple-to-use equipment. Further advances will allow more tests to be offered.



Roger Kirkbride, Pharmacy Consultant

Pharmacy consultant to the project Roger Kirkbride said: “Carrying out monitoring tests on site at the pharmacy is quicker for patients. But it also allows us to create a better link between medication and its effect, enabling us to modify a dosage there and then or advise on other lifestyle changes to help people better control their condition.”

Establishing community support networks

The voluntary and community sectors have significant expertise in supporting self care and self management. PCTs and Local Authorities should consider opportunities to work in partnership with these groups, including to develop joint training programmes to support the care of people with specific long term conditions.

More than 280 PCTs are involved in the Engaging Communities Learning Network (ECLN), facilitated by NatPaCT. Through the network, PCTs are sharing the best ways to engage communities, particularly through EPP courses. Burnley, Pendle and Rossendale PCT, for instance, is training EPP volunteer tutors to deliver the programme in a second language and looking at associated cultural issues such as whether the programmes should be offered to single gender groups.

NPDT's Healthy Communities Collaborative has created a template for multi-agency working, removed barriers which prevent statutory agencies from engaging with communities, and reduced falls in older people (32% reduction in the first year). The participating PCT sites were tasked with engaging teams of older local residents to begin work on falls prevention (and now nutrition). Some of the teams are 100% made up of older local people. The composition of the teams has had a very positive impact on the successful outcomes of the programme.

Implementing the NHS and Social Care Long Term Conditions Model

Key Actions

1. Identify the number of people locally with long term conditions, group according to their level of need.
2. Identify high-risk patients requiring pro-active case management.
3. Work with primary, secondary and social care to establish what services are available and where there are gaps.
4. Find ways of involving patients and their carers in planning services.
5. Plan and commission new and integrated services using the primary care and pharmacy contracts, practice-based commissioning as well as pooled budget arrangements between health and social care.
6. Establish a programme of support for developing a workforce with the skills and knowledge to deliver these services.

The NHS and Social Care Long Term Conditions Model is designed to be fully embedded into the way NHS and social care services deliver care to those with long term conditions. As a result, adopting the new approach will involve major organisational change. PCTs, supported by Strategic Health Authorities and working in partnership with Local Authorities will need to develop robust improvement plans for taking this forward, with an initial focus on implementing the case management approach to care.

Suggested steps to assist health communities implement the Model are set out at Annex 2.

Using data to drive planning

In order to plan and commission services for patients with long term conditions, health and social care partners, in partnership with patients, need to analyse and understand existing data showing:

- the number of those with long term conditions;
- the prevalence and types of long term conditions;
- the services available across the local health and social care systems to these patients;

- the flow of patients through primary and secondary care, including referral patterns and an analysis of why patients have unplanned admissions;
- the range of diagnostic and intermediate services available, and
- through analysis, the cohort of patients with the highest burdens of disease, at greatest risk of hospital admission and who would most benefit from pro-active, primary care-led case management of their condition.

Valuable information is available from a range of sources including public health departments, general practice, social services and the acute sector. Increasingly data quality in general practice will improve through the development of disease registers driven by the Quality and Outcomes Framework and through the information produced through practice-based commissioning.

Planning and commissioning services

When planning and commissioning services, PCTs, with their health and social care partners will need to consider all the components they have at their disposal.

PCTs should involve service users in the decision-making process and work to ensure services are fully integrated, diverse and offer patients real choice. A principle aim of local plans should be to ensure proper co-ordination so patients enjoy a seamless journey through the health and social care system.

When commissioning services, PCTs should draw up clear contracts, supported by service level agreements. Robust and timely monitoring will ensure delivery and compliance.

Primary care will continue to be at the heart of provision for those with long term conditions. The new primary care contracting arrangements provide an opportunity for primary care to take a more pro-active approach to meeting their needs. The Personal Medical Services and Alternative Personal Medical Services contracts can be used to extend the range of services and providers.

Hospitals will need to be fully engaged in the development of services and the support of the Nurse Executive Director in developing community matrons and the systems to support case management will be essential.

Local plans should also cover:

- **Pharmacy** – The new contractual framework for community pharmacy presents an opportunity to take a fresh look at the role of pharmacy in supporting people with long term conditions. Effective medicines management and repeat prescribing is critical. Community pharmacy can be a key player in testing and diagnosing, reviewing and educating patients about their conditions and how to manage them, medicines management, care co-ordination, and early recognition of deterioration in patients. Support for self care is included within the *essential services* which all pharmacies will provide. Where a pharmacy cannot itself provide the support or advice needed the

patient will be clearly sign-posted to other health or social care providers better able to assist.

- **Diagnostic services** – These are critical services to support the management of people with long term conditions. The best arrangement would be to have accessible services available in the community for use by primary care practitioners, without referral to outpatient departments.
- **Supporting patients to self care** – There is a range of activities that can be undertaken to help patients understand and become confident in managing their condition. This area is covered in detail in chapter four.
- **Intermediate care** – Intermediate care is important to support both primary care and secondary care.
- **Secondary care** – PCT commissioners should work with secondary care colleagues to plan ways of co-ordinating patient care, taking into account the impact of Choose and Book.
- **Out-of-hours services** – Out-of-hours services need to provide suitable support for patients with long term conditions. Case managers working with vulnerable, high-risk patients can develop supporting arrangements with out-of-hours service providers
- **The need for workforce planning** – Plans should recognise the contribution already being made by GPs, nurses, allied health professionals and practitioners with a special interest. In addition, they should look at ways of developing new, enhanced roles – including new case management roles such as community matrons – and expertise among their workforce.

Implementing case management for patients with complex long term conditions and high intensity needs

Key Actions

Health communities should develop a detailed local plan of how this new service will be introduced; how it will integrate with existing services, and how rapid progress can be made in both reducing hospital admissions and lengths of stay.

The following steps are indicative:

Stage 1

- PCTs, working with health, social care and other partners, to agree local plans and measurable input and output goals, that will support local implementation of the case management approach.
- PCTs, working with health, social care and other partners to agree how case managers will ensure locally that the needs of patients, identified in their care plans, are met in a timely manner.
- PCTs to decide who should provide all or each part of the case management service locally.

Stage 2

- Identify the most vulnerable patients using an agreed measure which provides a full list of all the patients in a PCT at risk of avoidable hospitalisation or institutionalisation.
- Boost numbers of community matrons and other case managers to match numbers of individuals identified as high risk. There is no minimum caseload, but we would anticipate that more than 80 highly complex patients on a single clinician's caseload would be unsustainable.
- Develop local systems to support on-the-job training and robust mentoring arrangements for case managers with GPs and consultants.

Stage 3

- Approach the patients identified as high risk and seek their agreement to be supported through case management.
- Develop single comprehensive care plans which are agreed between individuals and specialist clinicians (and all agencies), with all participants having a copy.
- Ensure these care plans set out agreed health objectives and care needs for the person and the contributions of the individual and of each agency to meeting these.
- Assess the possibility of providing self care skills training so that the individual is able to take better care of themselves.
- Ensure care plans also include arrangements for emergency or contingency arrangements.
- Identify and put in place data collection to support a programme to ensure patient satisfaction with the service provided.

Stage 4

- Share learning across other PCTs and wider health communities.

Embedding the NHS and Social Care Long Term Conditions Model

Many local health and social care communities across the country are already adopting the NHS and Social Care Model for people with long term conditions to meet local needs. Those that are using the Model most effectively are doing so by mainstreaming their approach across all areas of activity and by harnessing the techniques and tools they have at their disposal to make the approach work for them. These include:

Community support:

- encouraging patients to participate in community programmes;
- forming partnerships with community organisations to support and develop interventions, and
- working with Local Strategic Partnerships to strengthen multi-agency support and co-ordination.

Supported self care:

- helping patients to develop the knowledge and skills they need to manage and monitor their own conditions, including by providing self care tools such as blood pressure cuffs, diets and referrals to community resources;
- ensuring patients can be actively involved, if they wish, in planning their personalised care;
- encouraging people to set goals for improving the care of their condition;
- encouraging people to form self care support networks to provide peer support to one another;
- commissioning a range of self care support programmes including programmes which are lay- and professionally-led and generic and disease-specific programmes that include self-assessment, goal-setting, action-planning, problem-solving and follow-up, and
- developing lifestyle education programmes in physical activity, healthy eating and other healthy habits.

Decision support and clinical information systems:

- identifying the local population with long term conditions and sorting it into the three broad patient groups and approaches to care;
- embedding evidence-based national guidelines – such as National Service Frameworks, NICE guidance and the Quality and Outcomes Framework – as well as local guidelines and protocols, into daily clinical practice, including incorporating them into IT systems;
- integrating primary care and specialist expertise through clinical networks;
- developing faster, more convenient access to diagnosis and treatment;
- using technology to establish registers of patients with a particular long term conditions and linking these to guidelines which provide prompts and reminders about needed services;
- identifying individuals with the most complex and highest burdens of disease and supporting them with case management;
- developing systems to assure access to timely, relevant data about individual patients and populations of patients;
- using these systems to provide timely reminders for patients and clinicians, so ensuring call, recall, review and reassessment, and
- developing systems to monitor performances of co-ordinated care teams.

Health and social care system environment:

- developing a model that links the care provided to patients through the self care, disease management and case management approaches;
- using care planning to support care for all patients with long term conditions;
- provide case management for patients with the most complex conditions;
- establishing multi-disciplinary teams with clearly defined roles (including responsibilities for patient self care, pro-active follow up and resource co-ordination);
- developing planned interactions, including regular and systematic assessments, preventative interventions, follow ups and self care support, and
- ensuring continuity of care – all interventions should include active co-ordination between primary care teams, specialists and others.

Some key resources

Case management for patients with complex long term conditions and high intensity needs

- NatPaCT's Long Term Care web pages at www.natpact.nhs.uk
- The National Primary Care Development Team (NPDT) for the Primary Care Collaborative, the Primary Care Contracting Collaborative and Unique Care approach www.npdt.org
- London Older People's Services Development Programme
- The Innovations Forum
- Hospital Discharge Planning Guidance www.dh.gov.uk
- Pursuing Perfection www.modern.nhs.uk/scripts/default.asp?site_id=40

Disease management: improving pathways and protocols

- The NHS Modernisation Agency's Changing Workforce Programme plus a searchable Role Redesign Database. See www.modern.nhs.uk and follow the links to Workforce/ New ways of working.
- NatPaCT's Commissioning Friend for PCTs www.natpact.nhs.uk
- Pursuing Perfection www.modern.nhs.uk/scripts/default.asp?site_id=40
- Protocol-based care CD Rom – Modernisation Agency and NICE www.modern.nhs.uk/protocolbasedcare/
- ARMA Standards of Care for People with Inflammatory Arthritis, Osteoarthritis and back pain

Supporting Self Care

- The Expert Patient Programme information line 0845 606 6040 and EPP website www.expertpatients.nhs.uk
- The NPDT working with the EPP to improve management of care for people with long term conditions as part of the Primary Care Collaborative www.npdt.org
- The Diabetes X-PERT Programme at www.cgsupport.nhs.uk
- The Medicines Management Collaborative www.npc.co.uk/mms
- NPDT Healthy Communities Collaborative www.npdt.org

